# Vocabulary Task Force Transcript May 31, 2012

#### Roll Call

# **MacKenzie Robertson** — Office of the National Coordinator

Good morning, everyone. This is MacKenzie Robertson in the Office of the National Coordinator. This is a meeting of the HIT Standards Committee Vocabulary Task Force. This is a public call and there will be time for public comment at the end. The call's also being transcribed, so please be sure to identify yourself before speaking.

I'll go through role and then also ask any staff members on the line to also identify themselves.

Jamie Ferguson?

<u>Jamie Ferguson – Kaiser Permanente – Executive Director HIT Strategy & Policy</u>

Present.

## <u>MacKenzie Robertson — Office of the National Coordinator</u>

Thanks, Jamie. Betsy Humphreys?

#### Betsy Humphreys - National Library of Medicine - Deputy Director

Present.

# MacKenzie Robertson — Office of the National Coordinator

Thanks, Betsy. Donald Bechtel? Christopher Chute? Bob Dolin? Floyd Eisenberg? Patricia Greim? John Halamka? Stan Huff? John Klimek? Clem McDonald?

#### Clem McDonald - National Library of Medicine

Present.

#### MacKenzie Robertson — Office of the National Coordinator

Thanks, Clem. Stuart Nelson?

# Stuart Nelson - National Library of Medicine

Present.

#### **MacKenzie Robertson — Office of the National Coordinator**

Thanks, Stuart. Marjorie Rallins? Dan Vreeman?

#### Daniel Vreeman - Regenstrief Institute - Research Scientist

Present.

# MacKenzie Robertson — Office of the National Coordinator

Thanks, Dan. Jim Walker? Andrew Wiesenthal? Marjorie Greenberg?

Marjorie Greenberg – NCHS – Chief, C&PHDS

Here.

#### **MacKenzie Robertson — Office of the National Coordinator**

Thanks. And are there any staff members on the line?

#### M

... NLM

## Suresh Srinivasan - National Library of Medicine

Suresh Srinivasan from the NLM.

### Patricia Greim - VA - Health System Specialist, Terminology

Patricia Greim from VA.

#### MacKenzie Robertson — Office of the National Coordinator

Thanks, Patricia.

#### Asif Syed - American Medical Association

Asif Syed of the AMA.

## MacKenzie Robertson — Office of the National Coordinator

Okay. Jamie, I'll turn it back over to you.

### Jamie Ferguson - Kaiser Permanente - Executive Director HIT Strategy & Policy

Okay, great. Thanks very much, everyone, for joining today. We have two items on our agenda today. This is really actually a very exciting development and I'm really looking forward to this discussion. We're going to hear from Olivier at NLM about the approach to the Value Set Authority Center, including the curation of value sets.

And then we also want to reserve some time today for discussion about a possible guidance to eMeasure developers from the Health IT Standards Committee. And in this case it would be to—well I think these things fit very nicely together in terms of a discussion on direction for value sets in eMeasures in particular.

Is that agenda acceptable to everyone? Are there other things that folks feel we need to discuss today?

#### М

Somewhere in this process, it may be included, I think we should define what we mean and don't mean by value sets.

## Jamie Ferguson - Kaiser Permanente - Executive Director HIT Strategy & Policy

Okay. We did previously have that definition actually written by Betsy that was adopted by the Standards Committee. We can perhaps send that out, but I think just to recap, generally the value set—well, Betsy, you can do a better job of this than I can, between a convenience set and a value set.

# Betsy Humphreys - National Library of Medicine - Deputy Director

Yes. We're not talking about convenience or subsets like the frequently used or frequently seen subsets that NLM and others have been involved in developing, which are helpful to people when you're implementing, but that's not we're talking about. What we're talking about, as a value set, is a defined universe of all the values that are from a vocabulary that will be used for a particular purpose. To define a population for a quality measure or to populate a particular part of an HL7 message—

#### M

Got it. Thank you. That's clarifying and a good one.

#### Jamie Ferguson – Kaiser Permanente – Executive Director HIT Strategy & Policy

Okay. So I think then perhaps without further ado we should turn it over to Olivier to take us through the NLM presentation materials, which I believe were sent out and which are available on the web now.

## Olivier Bodenreider - National Library of Medicine

Thank you. So this is a presentation that we put together last week, I guess, and that we gave to the eMeasure developers. I'm going to show you select parts of this presentation because not all of this is appropriate in this particular context. So we're going to start with slide three. Do I need to advance the slides myself?

#### MacKenzie Robertson - Office of the National Coordinator

If you can just say, "Next slide," once I get them loaded up they'll advance them for you.

#### Olivier Bodenreider - National Library of Medicine

Okay. So if you can just go to three? Thank you.

So basically there are three elements that are important in the eMeasures. There are the measures themselves, but the measures rely on value sets to basically initiate some of the data elements that are referenced between the measures. And of course the value sets are sets of code that come from code systems, including RxNorm, SMOMED, LOINC and others. Can you click through? This is just to show that basically the eMeasure developers deal with the value sets, define some of these value sets, and if you click again there's another articulation here between the value sets and the code systems. Of course the value sets need to be curated and someone needs to make sure that the older codes in the value set are actually part of the given code system and that they are not obsolete and these kinds of things.

The point here is that it's not necessarily the measure developers or in the best position for doing this kind of curation. And the way we see things is that they are actually two different activities. One is to create value sets for use in eMeasures. The other one is to curate some of these value sets in reference to the code systems and to ... of the code system, and that's where we see NLM's particular intervention. Next?

So basically the point here is that in order to develop value sets we need to interact with terminologies and we need Terminology Services in order to define codes using various kinds of mechanisms, including synonyms and approximate measures. And of course another useful thing is to be able to exploit the structure of the code systems themselves. For example, get all the descendants of the given cancer, all particulars requiring fluoroscopy, for example. That's one example. Another example in the domain of drugs would be to refer to therapeutic classes or to classes in general. Next?

So the two elements of the curation of value sets are basically first to ensure referential integrity and the other one is to avoid duplication. Just to ... these two points, when we first looked at the value sets, 1,600 or so used in the 130 measures that were retooled by NQF and published earlier this year, we found actually a number of issues with the codes in this value set.

We found basically that 20% of the value sets had some kind of issues, either codes that were existing in the code system from which they were supposed to come or codes that were no longer valid in these code systems or different types of errors. And these 20% of the value sets that had errors actually impacted 80% of the eMeasures. That's just to give you an idea of the importance of the problem.

So the first thing that we need to do is to make sure that there is referential integrity, and what I mean is that all the codes in a given value set need to be valid codes in the corresponding code system. An example of errors here is in the first example. The code that was used for a term was actually not the code for the concept but the code for the string itself. It's not a ... . And of course one can be inferred from the other, but that's not what should be in the value set in the first place.

Another example of a common problem is a problem with state codes, codes that were valid at the given point in time but that are no longer valid. The example is from RxNorm where Amoxicillin 25 MG/ML Oral Suspension basically changed codes at some point in time for reasons that are specific to the way RxNorm handles its drugs and the editorial guidelines that RxNorm has.

The second issue is duplication. When we look at these 1,600 value sets we found a number of duplicates, including exact duplicates for value sets that were created by the same measure .... So of course what it tells us is that there was probably no way by which they could check that the value set already existed and we should be able to do a better job at showing them what already exists. It's part of the curation process. Next.

So curating the value set is one thing, but another part of what NLM could do is be involved in the delivery of the value sets. There needs to be some kind of authoritative sensor providing the curated value sets and providing the latest versions of these value sets. And of course, the earlier versions would need to be archived and available for reference, but we need to make sure that the latest version of the value set and of the terminologies are used.

In terms of format, what becomes clear is that there's a need for two things. The value sets need to be readable by humans in some kind of HTML format, but they need to be accessible to machines also, and XML comes to mind when it comes to that. Next.

So that's basically the overview of a possible system that we've been discussing with the Office of the National Coordinator and I. So one slide from Jacob Reider is on here. What it shows us here is the part that I talked about that could be handled by NLM, in the middle, with both the curation and the delivery of the value sets. The value sets are delivered for consumption by humans and machines, and that's for interface with the vendors, with providers, in public health organizations, for example.

And we would need this to be implemented fairly quickly. Mainly it would need to be available for using meaningful use too and the deadline we're looking at, at this point, is something early next fall.

And in the next stage, what we envision is that the curation system—so to do the curation of existing value sets over the summer, but in the longer run we would like the authoring environment to directly interface with the terminology services that NLM provides and the curation services provide to make sure that—for example, to make it easy for a measure developer to see if a value set already exists so that they could avoid the kind of duplications that I talked about.

We can advance to slide 12. Thank you. So in the slides that I just addressed, I was explaining to the eMeasure developers the background that NLM has and the work that NLM's has done in the past to dedicate or so about terminology, terminology integration and terminology services. And my point was to tie the Terminology Services to both the curation of the value sets and development also of the value sets.

So again, the two points here for curation are referential integrity and being able to show similarity among value sets. We need to be able to make sure that a code does exist in a given code system. We need to be able to make sure that we're referring to a specific version of a code system, and NLM archives several versions in the UMLS. And we need to provide services so that codes that have become obsolete can be remapped to the conversion of the entities that they point to.

That's for the codes themselves. In the value sets a term is usually affiliated with the code. And of course as part of the curation process one also needs to make sure that the term matches the code and the other way around. And we've seen examples of lack of match in the value sets that we've looked at.

The second point was to avoid duplication. And in order to avoid duplication we need to be able to assess similarity between value sets or among value sets and we can do that in several ways. Of course the UMLS concept mappings can help identify similar value sets across code systems, because the codes will be mapped to the same UMLS concept.

Another important part here is to make sure that we can recognize the intentional and the extensional definitions of the value sets. By intentional I mean—say for example all descendants of myocardial infarction, which could be the value set representing all instances of myocardial infarction if you wish. And the extensional definition is what needs to be provided in these eMeasures, which is the list of all possible values corresponding to this value set. And of course Terminology Services and being able to

traverse these terminologies, the structure of these terminologies is a good way of reconciling the intentional and the extensional definitions.

Of course we also need to inform the value set developers of any changes occurring in the code systems so that the value sets could be adapted accordingly. And as part of the curation process, any change made to the value sets by the measure developers will need to be evaluated and recurated by NLM. Next.

So the value sets are useful not only for the curation after the fact, if you wish, but are useful for the development and hopefully will prevent some of the errors that we've found in our analysis of the value sets. And as I mentioned earlier, we envision a system in which the authoring tools, for example the measurer of Phase 2, would be able to be interfaced directly through an API with the terminology services and the curation services developed at NLM.

Again, this would ensure referential integrity. This would provide access to the latest version of the curated value sets, existing value sets and possibly avoid the creation of duplicates.

Overall, I think the most important point, going back to the first slide that I showed, was that the value sets are really at the interface between the eMeasurers and the code system. And that would help the eMeasure developer's focus on the value sets and not necessarily on the terminology itself, because this terminology would be handled through the Terminology Services. Next?

So what would a value set repository look like? We see it as a one-stop shop, if you will, for all the value sets used for meaningful use, especially if we use phase 2. Of course it could have other values sets as well, but right now we're focusing on these ones.

It would be an authoritative source, which means that you would be sure that there you find the curated value set and that you find the latest version of a given value set.

It would be publicly available. It doesn't necessarily mean that it's completely open and that all the value sets would be in the public domain. We understand that there are copyrights and licensing restrictions. That NLM is well equipped with the UMLS Terminology Services already and the infrastructure of the UTS to provide authentication services as part of the terminology services.

And this value set repository would be used by not only the eMeasure developers to check the existence of value sets, but—I just lost my screen—it would be used also by the value set developers for them to get the terminologies and by the implementers of the value sets, vendors and others, because that would be their source of curated value sets for implementation purposes. Next.

Of course the value sets are not just a list of codes. With these codes come metadata. First, we need an identifier for this value set and ... being an OID. We need an indication of the version. Who created the value set? When was it created? What is the purpose? When it was developed and these kinds of things?

So this constitutes the metadata that are associated with the value set. There are several ways of representing this metadata. One that we are looking at right now is the IHE Sharing Value Sets set of metadata, but of course there are also metadata that are listed as part of CTS2 and we are looking at this at well. Next.

So I'm going to end up with the delivery side of the value sets. We need to provide access to the value sets in several different ways, by the name of the value set but also by the author of the identifier value sets. We need to be able to search all the value sets that contain the given codes, for example, and we can use the metadata to search the value sets.

For the value sets that are retrieved, again we want to display them for human consumption, but also and probably more importantly, to make them available for direct use by computers through an API and in XML.

With that, I'm happy to answer any questions and Suresh will also answer questions.

#### Jamie Ferguson - Kaiser Permanente - Executive Director HIT Strategy & Policy

Olivier, thank you very much. This is Jamie. So let me just open it up to the taskforce members and participants on the call for questions first.

# <u>Clem McDonald – National Library of Medicine</u>

Let me propose a question. This is Clem. I think that the idea of having a repository is clear and wise. By experience with developers and various things is they all work in spreadsheets. I've tried to build tools for them in the past and it hasn't worked out. So I wonder if you're thinking that they will still build these spreadsheets and send something or whether they'll be working online directly in a tool that comes from NLM?

#### Betsy Humphreys - National Library of Medicine - Deputy Director

Clem, this is Betsy. I think the assumption is both. That some will and some won't. I mean some will use the tools to create them and some will use other tools, and then we'll have to have mechanisms for uploading validation.

## Clem McDonald - National Library of Medicine

Okay.

# <u>Jamie Ferguson – Kaiser Permanente – Executive Director HIT Strategy & Policy</u>

This is Jamie. I think my question is about synchronizing the metadata for these value sets that are contained in the repository with the metadata, both the scope of metadata as well as any updates that may come from the standards bodies themselves. And I'm thinking particular of ..., which has a project for defining sets of metadata and a process for maintaining metadata on SNOMED RefSets, some of which could be related to or embodied in these value sets. And so I'm wondering about that synchronization.

## <u>Betsy Humphreys – National Library of Medicine – Deputy Director</u>

I'll take a stab at that. This is Betsy. I think that we would be interested obviously in figuring out how to provide access to any existing sets that people might use as the basis for sets here in the United States, and that might include those. I think that we would have to figure out—there's been a recommendation, as I understand it, by the Clinical Quality Working Group about which set of metadata and standards we should use for this. And it is sort of the combination of the EHI saying and the CTS2 standard. So my feeling is that we would have to see how that maps onto exactly what's being used in the RefSets.

## Jamie Ferguson - Kaiser Permanente - Executive Director HIT Strategy & Policy

Okay, thank you.

# Betsy Humphreys - National Library of Medicine - Deputy Director

I mean, because I think that we have this recommendation, which sort of seems reasonable. Suresh, you may know more about the RefSet metadata than I do.

# <u>Suresh Srinivasan – National Library of Medicine</u>

Yes. This is Suresh from NLM. We're actually just starting to get some experience building SNOMED RefSets. We have, for example, the rider the administration. Right now it's just a simple subset of SNOMED, but eventually we want to publish that as a RF2 RefSet. So I think any experience we gain from that effort will be ruled into this value set effort as well. So I think our process to kind of unify and come up with a union of all the metadata elements that seem to be useful in this regard.

### <u>Clem McDonald – National Library of Medicine</u>

From my perspective, that is the right answer.

# <u>Suresh Srinivasan – National Library of Medicine</u>

Thank you.

## Jamie Ferguson - Kaiser Permanente - Executive Director HIT Strategy & Policy

Other questions and discussions?

#### Ram Sriram - National Institute of Standards and Technology

This is Ram Sriram from the NIST. The question I have is two questions. One is the validation of this value sets. I guess you have a process for that. And the second one is the long-term storage of the value sets in terms of like five years from now what happens and things like that? Is there a plan for that?

#### Suresh Srinivasan - National Library of Medicine

Yes. This is Suresh again. So what Olivier was talking about is kinds of things we're doing, things we're starting to think about for validating value sets. So this a growing list of, if you would, Q&A queries against both the code systems and the value sets themselves.

So we want to keep that list and make it kind of an active set of things we check for. And absolutely, the long-term storage is nothing that's deleted. So the web services, APIs and interactive access should provide you ways to get to all the versions of these value sets.

#### Olivier Bodenreider – National Library of Medicine

And by the way—this is Olivier Bodenreider. By the way that's exactly what we are doing for the code systems in the UMLS, because the archives of the UMLS that are available online and for the API you can access a given vintage version of SNOMED from several years ago. So for us it's just going to be the same thing but with the value sets.

## Clem McDonald - National Library of Medicine

One other question from Clem. So it's apropos of the ... have RefSets. So RxNorm is sort of special because it's intrinsic to NLM and it's updated very rapidly. SNOMED CT, LOINC, CPT, other things that might be in parts of value sets are updated less frequently, yearly or biyearly or something. What would API do for the code sets that aren't internal to SNOMED, as the active place they're built?

#### Suresh Srinivasan - National Library of Medicine

Clem, this is Suresh. Did you mean internal to the UMLS?

#### Clem McDonald - National Library of Medicine

Well UMLS is out of phase, usually, by some months compared to RxNorm. No, I mean I don't know what you meant by APIs. I thought maybe you would have an API directly to SNOMED CT, for example, and then you could therefore get the fresh one that's cooking or just got cooked.

#### **Suresh Srinivasan – National Library of Medicine**

Yes, this is still up for thought and discussion here, but the way we're looking at it now is the UMLS CTI will provide access to the terminologies in the UMLS based on the UMLS schedule, which is roughly May and November. But obviously we're going to have RxNorm coming out monthly, LOINC, etc. So the value set has to be a little more responsive than being six months out of date.

# <u>Betsy Humphreys – National Library of Medicine – Deputy Director</u>

This is Betsy. That's absolutely true, but there's also the schedule for the curation of the value set from the point of view of the actual people who are responsible for it and for its clinical content. And we obviously are going to have to work this out very carefully, because there obviously are some additions to measure sets, value sets that you would want to make.

An example would be whether ... is sort of relatively sudden introduction into use of a new text for something and that text is very important in terms of a set of tests for a measure set or new drugs and things. But these things can't be, normally will not be changed instantaneously because of requirements of CMS to measure them and to make them available and have them be static, at least for a time. So there's a whole lot of working out of these details.

## Jamie Ferguson - Kaiser Permanente - Executive Director HIT Strategy & Policy

This is Jamie. Thank you, Betsy, because you practically took the words out of my mouth. I also just want to remind folks that the versioning of the value sets for eMeasures that are used in programs like Meaningful Use, in particular, are likely to be fixed in regulatory text that will be changing on a less frequent basis.

And so the general approach that the Office of the National Coordinator has outlined is a minimum standards approach saying that the standard, at a minimum, has to be X and then using, in this case, additional values in a value set or other parts of the standard, for example, would be optional. And so I think that we also have to consider the publication and curation of that minimum set in addition to the more updated or the broader set that may be used by some folks optionally.

#### Daniel Vreeman - Regenstrief Institute - Research Scientist

Yes, I think this question of timing is a good one. This is Dan Vreeman from Regenstrief. I was going to bring it up too because I was thinking about sequencing, and on the LOINC side we've already seen sort of a wave of new requests for concepts related to eMeasures, as folks have been trying to work out and retool them. I think it is very clear that there'll be new concepts added and they'll be sort of expecting them to be ready as soon as they're sort of published. And so waiting not only for the LOINC release or a SNOWMED release in addition to some other delays, I think it'll be challenging, I guess, just to wind up all the publications dates.

#### Clem McDonald - National Library of Medicine

Well working that quickly I think you might want to think about APIs directly to some of the value sets so you don't have any synchrony problems. I don't know if that's feasible.

#### Olivier Bodenreider - National Library of Medicine

This is Olivier. We already have, for the one that changes the most frequently, which is RxNorm to ..., we already have an API to this one and that's what we've used in our analysis of the value sets. But another point that I want to make is that in the obsolete codes that we've studied it was usually not the problem of something that should've came up this month versus last month. It was more like codes from three years ago compared to today.

So I know that's a serious problem and we need to pay attention to—we need to make the latest versions available, but again, by enlarge, the scale of the time discrepancies that we observed was much bigger than just last week's version compared to this week.

## Clem McDonald - National Library of Medicine

Well it's not what's wrong; it's what's not in there is what's going to cause the stress in the environment. Betsy brought up the example. So there's a new HIV test that's going to be required for confirmation, the best we can gather by CDC and other expert bodies, instead of the immunoblot. So if, for example, that test was—if they were trying to check on something of HIV and that doesn't get into the cycle for six months or a year, a lot of people will be dinged for having not done something they actually did, and then you'll have a big political backlash.

#### Betsy Humphreys - National Library of Medicine - Deputy Director

I think we can be brighter than this.

## **Clem McDonald - National Library of Medicine**

... open the thought to having a direct API to major vocabularies. I don't know, maybe that's hopeless.

#### Suresh Srinivasan - National Library of Medicine

One thing—this is Suresh from NLM. One thing, at least on the SNOMED side of it, is the U.S. extension of SNOMED. We're working on creating a quick way to assign a permanent identifier to a SNOMED concept. And you can use that in creating your value sets, for example, sooner than when SNOMED or the extension comes out.

## Betsy Humphreys - National Library of Medicine - Deputy Director

Clem, I think that the problem is there. So what we'll just have to do is figure out a sensible way to solve it, and I bet there is one.

## Clem McDonald - National Library of Medicine

Okay. And the second thing, not a question, it's sort of a thought, is that given this additional power in let's say particularly RxNorm, could we get value set developers to define the value sets as an algorithm rather than as a list, because that way things will get taken care of automatically? ... apply to all, but it certainly would work well in RxNorm.

# Betsy Humphreys - National Library of Medicine - Deputy Director

I think that my understanding is that, at least at this juncture, probably for meaningful use dates too, others can correct me if I'm wrong, I think CMS is going to be pretty definite that in order to make sure everything's working right it needs to be a list.

## <u>Suresh Srinivasan – National Library of Medicine</u>

Yes. An enumerated list of codes is the approach for now.

#### Stuart Nelson - National Library of Medicine

This is Stuart. That's exactly where the problems are going to lie, in terms of timing in an area that changes rapidly, is that if you have an enumerated list of codes, you're going to be missing all the latest codes.

## **Clem McDonald - National Library of Medicine**

Yes. Whereas you just said "patents" you'd cover whatever just came out.

# Suresh Srinivasan - National Library of Medicine

That's exactly right, but that's why the Office of the National Coordinator has outlined the approach of requiring what they call minimum standards, and then allowing optionally the use of a more updated version.

#### <u>Jamie Ferguson – Kaiser Permanente – Executive Director HIT Strategy & Policy</u>

This is Jamie. I just wanted to recap a little bit. It sounds like there's a very strong support and agreement on this direction that NLM has taken in terms of the Value Set Authority Center. We've discussed a number of different issues on timing and versioning and updating of value sets and vocabularies. We've also talked about the approach on metadata and coordination with developer processes. Are there other broad topics in this discussion that have not yet been brought up?

#### Marc Overhage - Siemens - CMIO, Health Services Business Unit

This is Marc Overhage. One other thing that we haven't touched on that I find an ongoing challenge is we talk about trying to keep these as unique value sets and yet often times they find that the options in value sets are highly variable by the clinical setting. So you either end up with a large collection of heavily overlapping value sets or you end up with one large value set that is sort of the super set that from a user standpoint isn't necessarily easy, and we didn't really talk too much about that, I don't think.

## Olivier Bodenreider - National Library of Medicine

This is Olivier Bodenreider. So I focused on the full-term ..., and what we've been discussing with UMLS in the past couple weeks is also a longer-term version of just the thought of curation and that will include harmonization. Of course it's important to reconcile value sets that are potentially related and that are potentially ... of one another, not just the duplicate variance.

Because of course when you start looking at scenarios you mentioned that you can find one value set that has nine codes and another one that has the same nine codes plus another one. So it's the tenth one in outlier that has nothing to do there and is it a mistake or is the one with nine coding complete? So that's the kind of thing that we'll be able to start looking at very seriously. But that's certainly not

something that we'll be able to do this summer and ... for implementation as meaningful use too. That's more for the long term.

## Suresh Srinivasan - National Library of Medicine

This is Suresh. I think one of the things Olivier alluded to is the ability for a value set author to say, come to the value set center and say, "Are there similar value sets to this that I'm defining now?" And based on that, they can make the decision as to whether they should merge with the other ones or use the other ones for their purpose. So I think those kinds of functionalities would be absolutely critical.

#### Marc Overhage - Siemens - CMIO, Health Services Business Unit

Part of the reason I ask about that is just your experience as we watch the measure developers, for example, and the tendency that is probably natural for everybody to get their very specific narrow view of what the right answer is, and then you just end up with this proliferation that's not very useful. And that's kind of what we've seen with the measures and where beta blockers—there's a concept, I think, there were 14 or 15 different definitions of beta blockers in the eMeasures that were retooled for stage 1. That's just an ongoing challenge. I mean it's a challenge period, whether you're doing it in a tool or a spreadsheet or not. It's something that I think we need to be cognoscente of as we think we're going to catalog these.

# <u>Jamie Ferguson – Kaiser Permanente – Executive Director HIT Strategy & Policy</u>

Okay, great. Are there any other comments on this work on value sets?

## Patricia Greim - VA - Health System Specialist, Terminology

This is Patricia Greim from VA. I think it's most impressive that the National Library of Medicine is willing to step up and provide this very needed service.

## Marjorie Greenberg - NCHS - Chief, C&PHDS

This is Marjorie Greenberg. I would certainly agree with that. I know we talked about this maybe more than a year ago and they've just been quietly doing it. So it's very gratifying to hear about it. Thank you.

# <u>Clem McDonald – National Library of Medicine</u>

We should have some dialogue with CDC, which has some similar functionality in mind and in place, I think, for .... but at least to—

# Betsy Humphreys - National Library of Medicine - Deputy Director

This is Betsy. I think that that some of that is already going on, Clem.

#### Marjorie Greenberg – NCHS – Chief, C&PHDS

I know I was on at least one teleconference in which that collaboration was evident, but certainly that's a good point.

#### Nancy Orvis - U.S. Department of Defense (Health Affairs) - Chief

This is Nancy Orvis in DOD. I'm glad to see this too. I would also like if someone could just directly send me the slide presentation because I can't seem to download it off Adobe.

#### Clem McDonald - National Library of Medicine

I got an e-mail before. You didn't get it yesterday or whatever?

# Betsy Humphreys - National Library of Medicine - Deputy Director

I should've been off the invite, I think.

# <u>Clem McDonald – National Library of Medicine</u>

... calendar.

## Nancy Orvis - U.S. Department of Defense (Health Affairs) - Chief

Thank you.

#### MacKenzie Robertson — Office of the National Coordinator

Hi, this is MacKenzie. It wouldn't have been—it's not attached to the calendar invite, but an e-mail did go out from the Office of the National Coordinator ... e-mail account.

## Nancy Orvis - U.S. Department of Defense (Health Affairs) - Chief

Thank you.

# Jamie Ferguson - Kaiser Permanente - Executive Director HIT Strategy & Policy

This is Jamie. So thank you very much for the presentation, Olivier, and the great work by all the NLM staff on this, and thanks to all the members of the taskforce for your thoughtful comments and discussion.

I do want to move us on to our next and related agenda item, which is that, Jim Walker, the Chairman of the Clinical Quality Group for the Standards Committee, as well as John Halamka and John ... and a number of others have voiced their support for an idea that the Standards Committee ought to provide some guidance to measure developers in terms of constraining the value sets that are used. I think this is based in part on a number of the public comments that were made on the originally proposed eMeasures and on some of the more recent activity by measure developers requesting, in some cases, precoordinated terms to cover large parts of proposed eMeasures.

I think the basis idea is that certainly there are cases where new or different type of documentation is intended to be forced, if you will, through the introduction of new concepts in eMeasures, but in general, that's the exception. So the basic idea is that the eMeasure developers in general should use concepts and terms and codes that are already used in documentation for which there's evidence that these things actually exist in the wild. And both not make up new things that are not used needlessly or without a good policy reason, but also not to use codes in value sets that may be perfectly valid but that just don't really occur naturally in documentation.

So the idea of providing this guidance is something along the lines of saying, and I think the NLM's experience with the creating the core problem list is a good example of this. A number of SNOMED users in that case, including, I believe, Kaiser where I work, as well as the VA and Harvard and others said, "Well these are all the SNOMED codes that we actually use for problems." So you can see that there's a large body of evidence for, whether it's the top 2,000 or the top 5,000 or some number of items that are used there.

# Betsy Humphreys - National Library of Medicine - Deputy Director

Jamie?

#### Jamie Ferguson - Kaiser Permanente - Executive Director HIT Strategy & Policy

Yes?

# <u>Betsy Humphreys – National Library of Medicine – Deputy Director</u>

This is Betsy. Let me interrupt and say, just so you understand, we actually took from whatever vocabulary they were using, many of which were local, were their top problems and then we connected them to SNOMED. In the case of Kaiser, of course, the data were often usually SNOMED or CMT, but local extensions. But for some of the others it was basically whatever terminology they were using we were taking the top, the most frequent, and then mapping that to SNOMED.

# <u>Jamie Ferguson – Kaiser Permanente – Executive Director HIT Strategy & Policy</u>

Yes, thank you for that clarification. But I think the basic idea of the Standards Committee providing this guidance to the measure developers would be to identify those cases in which there is a policy reason to use the eMeasures as a forcing function for different or new styles of documentation, but otherwise to advise the measure developers to constrain their value sets, the things that are actually used.

So I'd like to open the floor to discussion on that idea.

# Marjorie Rallins - AMA - Director, CPT Clinical Informatics

This is Marjorie Rallins and I'm driving if there's a lot of background noise. Can you hear me okay? I just wanted to make some comments and I appreciate and agree with the recommendation.

From the PCPI perspective, a measure developer perspective, we have been creating new concepts for things that did not exist at all in SNOMED. Our perspective is also that we are not creating new concepts for the sake of reporting on performance measures. That's for things that should exist for clinical documentation. And so I can speak from the PCPI perspective, and I think that is in alignment with the recommendation.

#### **Clem McDonald - National Library of Medicine**

This is Clem. Jamie, I think I support the goals a million percent. As I read the NPRM, I saw lots and lots of rules that would require lots and lots of new fields to be entered by clinical people, and I could see the gradual grinding of the gears so that no patient will get seen.

So I think that if that's sort of the intent, that we take stuff that's already collected and use it for rules and not invent sheets and sheets of new questions that have to be answered. Whether they're old codes or new codes that would be a very good thing for Clinical Care. Maybe I'm off target.

## Jamie Ferguson - Kaiser Permanente - Executive Director HIT Strategy & Policy

No, I think that's exactly the intent of this proposed recommendation. Other views?

## Daniel Vreeman - Regenstrief Institute - Research Scientist

This is Dan Vreeman. I too support the general idea. One of the things we've had some conversations about and it's a little bit more subtle than what's collected or not collected, but the way the data is represented. So for example, there is a lot of interest in change over time for various measurements. So you might have a blood pressure and everyone's using the standard systolic blood pressure code, but what the measure needs is a change, a delta, from one time point to another.

So in the measure they need some kind of a handle to attach that change value on and so they might need a code for that, but that's not the code that would exist in anybody's system. They would have the single point-in-time measurement. So there are some subtleties that might come out of this process, but it's all a matter of aligning the perspectives.

## Clem McDonald - National Library of Medicine

And maybe that can be handled by a rule rather than a list, but I guess that's not allowed yet.

#### <u>Daniel Vreeman – Regenstrief Institute – Research Scientist</u>

Right. Well and it's a matter of how it's—certainly it could be computed, but I think the point was they needed an identifier for when that's transmitted that this is change. So yes, it just gets tricky.

#### <u>Clem McDonald – National Library of Medicine</u>

Well I would support, Jamie, that the HIT Committee would try to come up with some guidance that would focus the measure developers and things that exist in the wild and existing computer systems or should, by enlarge. And we know there are lots of things. There are discharge diagnoses. There are medications. There are laboratory tests. There are blood pressures. There are all kinds of things that are now put into the computer and are fair game. There are lots of things we could think of that would require more effort and we should at least think twice about those.

## Jamie Ferguson - Kaiser Permanente - Executive Director HIT Strategy & Policy

And this is not to say that there won't be cases where something new or different is intended to be required and that the authorities reach agreement that something new is needed. So it's not intended to prohibit that, but it's also intended to, as you said, use what exists.

## **Clem McDonald - National Library of Medicine**

The other thing we found back when we were making rules at Regenstrief was if you thought long and hard about it the term you would think about instantly may not be in there, but there were a lot of good surrogates that came very close for statistical purposes. No one can actually approximate things by looking at drug usage or looking at test uses or theological measurements or scheduled appointments and those kinds of things.

## Jamie Ferguson - Kaiser Permanente - Executive Director HIT Strategy & Policy

Are there any other views or comments on this idea?

## Marjorie Rallins - AMA - Director, CPT Clinical Informatics

This is Marjorie again. One of the, I think, challenges that we're going to have with using what exists is the actual measure developers do not have the terminology experience to craft the measures initially so that you're able to capture what already exists. Just making that as a comment doesn't mean that the recommendation .... I think it really is. I just think it's something we'll have to consider.

## Jamie Ferguson - Kaiser Permanente - Executive Director HIT Strategy & Policy

Marjorie, this is Jamie. So that's a great idea. That's a great point. I think it leads to an idea that perhaps the NLM could serve an additional useful function by informing the measure developers of what does exist and publishing that kind of information that they may be able to receive from implementers and practitioners.

#### Betsy Humphreys – National Library of Medicine – Deputy Director

This is Betsy. I think it's very true that going forward we're going to have to have some sort of terminology expertise assistance, whatever, consulting that's available under some mechanism to people who are working on value sets for whatever reason. It's going to be interesting to see how we make that happen and what's the best way to do it.

We're constrained obviously in terms of aggressive timelines for getting something up on these stage 2 measures, and we may be able to build better approaches to assistance in all of this in the future. We're probably just going to have to do the best we can for this deadline coming up this fall.

## Jamie Ferguson - Kaiser Permanente - Executive Director HIT Strategy & Policy

Okay. I'm afraid—

# Nancy Orvis - U.S. Department of Defense (Health Affairs) - Chief

Jamie?

#### <u>Jamie Ferguson – Kaiser Permanente – Executive Director HIT Strategy & Policy</u>

Yes, sorry, go ahead.

#### Nancy Orvis - U.S. Department of Defense (Health Affairs) - Chief

This is Nancy Orvis. I have one question on given the—once these are done and the distribution of them, are we planning that whenever you go look at the meaningful use criteria that there will be a hyper link or something to these value sets for this particular criteria or measure or is it going to be a three or four step type of thing?

# <u>Betsy Humphreys – National Library of Medicine – Deputy Director</u>

I think that obviously the goal is to have it be as easy for people to get the stuff they need as possible. We're going to have to work out exactly how to do that.

# Nancy Orvis - U.S. Department of Defense (Health Affairs) - Chief

I'd be willing to help with that. Maybe I'll talk to Trish Grime offline, because one of the things—the implementation of these things, I want to publish this list of criteria and standards that'll come out with

meaningful use. And I want to have either hyperlinks and say, "And here are all the value sets for these particular things." So I can send them to several developers or implementers.

# Betsy Humphreys - National Library of Medicine - Deputy Director

We will talk about that.

#### Jamie Ferguson - Kaiser Permanente - Executive Director HIT Strategy & Policy

This is Jamie and I appreciate the conversation, but in the interest of time we are going to have to cut it off. I'm sorry to say we have reached the end of our hour.

## <u>Betsy Humphreys – National Library of Medicine – Deputy Director</u>

You have to open it up for the public though.

## Jamie Ferguson – Kaiser Permanente – Executive Director HIT Strategy & Policy

And we have to open it up for public comment, exactly.

# **Public Comment**

#### <u>MacKenzie Robertson — Office of the National Coordinator</u>

Okay, operator, can you please open the lines for public comment?

#### Operator

If you'd like to make a comment, please press \*1 at this time. Again, press \*1 to be placed into the comment queue. You have a comment from Carol Bickford.

# **Carol Bickford - American Nurses Association**

This is Carol Bickford from the American Nurses Association. Can you identify the National Library of Medicine who I need to speak to, to move forward on discussion of utilizing the resources that have just been described, in dealing with our nursing terminology space and ensuring that that's a patient representation of symptoms and sings and so on and intervention can be incorporated in this work moving forward? Who should I speak to?

# Betsy Humphreys - National Library of Medicine - Deputy Director

Carol, this is Betsy. I guess you better get in touch with me. But of course what we're talking about here in terms of the value sets, NLM is not defining the value sets. The measure developers are. We're providing a service to help curate and make them available and create them, but not making the decisions about what goes in them.

#### **Carol Bickford – American Nurses Association**

I understand that, but we do have a stake in that game as well in working on some of the measures. And the second question is, is this representation of this new capacity of NLM identified on the website in some way for those of us who need to do some rapid remediation?

## Betsy Humphreys - National Library of Medicine - Deputy Director

Just to say that you have seen the presentation of what we are going to do. It doesn't exist yet.

# <u>Carol Bickford – American Nurses Association</u>

Okay. Will there be ... in the future that as it gets more morphed into semblance of reality that that will be part of the resourcing on the website to help us understand what's going on?

# <u>Betsy Humphreys – National Library of Medicine – Deputy Director</u>

Absolutely.

# **Carol Bickford – American Nurses Association**

Thank you.

# <u>Jamie Ferguson – Kaiser Permanente – Executive Director HIT Strategy & Policy</u>

Okay, are there any other public comments?

# **Operator**

No. We do not have any other public comments.

# <u>Jamie Ferguson – Kaiser Permanente – Executive Director HIT Strategy & Policy</u>

Okay. So then we are adjourned. Thank you, everybody, for participating today, I appreciate it.